



GENERAL ASSEMBLY

COMMONWEALTH OF KENTUCKY

2015 REGULAR SESSION

SENATE CONCURRENT RESOLUTION NO. 108

TUESDAY, FEBRUARY 24, 2015

The following concurrent resolution was reported to the House from the Senate and ordered to be printed.

RECEIVED AND FILED
DATE March 19, 2015
2:39pm
ALISON LUNDERGAN GRIMES
SECRETARY OF STATE
COMMONWEALTH OF KENTUCKY
BY K. Adles

1 A CONCURRENT RESOLUTION designating February 28, 2015, as Rare Disease
2 Day in Kentucky.

3 WHEREAS, there are over 6,800 rare diseases afflicting nearly 30 million people in
4 the United States and thousands of Kentuckians; and

5 WHEREAS, children with rare genetic diseases account for more than half of the
6 population affected by rare diseases in the United States; and

7 WHEREAS, many rare diseases are serious, life-threatening, and lack an effective
8 treatment; and

9 WHEREAS, rare diseases and conditions include epidermolysis bullosa, progeria,
10 sickle cell anemia, Tay-Sachs, cystic fibrosis, many childhood cancers, and fibrodysplasia
11 ossificans progressive; and

12 WHEREAS, people with rare diseases experience challenges that include difficulty
13 in obtaining an accurate diagnosis, limited treatment options, and difficulty finding
14 physicians or treatment centers with expertise in their diseases; and

15 WHEREAS, great strides have been made in research and treatment for rare
16 diseases as a result of the federal Orphan Drug Act and amendments made to that Act;
17 and

18 WHEREAS, both the United States Food and Drug Administration and the National
19 Institutes of Health have established special offices to advocate for rare disease research
20 and treatments; and

21 WHEREAS, the National Organization for Rare Disorders, an organization
22 established in 1983 to provide services to, and advocate on behalf of, patients with rare
23 diseases, was a primary force behind the enactment of the Orphan Drug Act and remains
24 a critical public voice for people with rare diseases; and

25 WHEREAS, the National Organization for Rare Disorders sponsors Rare Disease
26 Day in the United States to increase public awareness of rare diseases; and

27 WHEREAS, Rare Disease Day has become a global event occurring annually on the


1 last day of February; and

2 WHEREAS, this body joins millions around the world in observing Rare Disease
3 Day and recognizes the 2014 world focus on continuing to find ways to work together to
4 provide the different kinds of care that people living with a rare disease need;

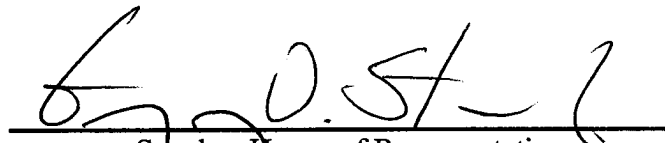
5 NOW, THEREFORE,

6 *Be it resolved by the Senate of the General Assembly of the Commonwealth of*
7 *Kentucky, the House of Representatives concurring therein:*

8 ➔Section 1. The Senate and the House of Representatives designate February 28,
9 2015, as Rare Disease Day across the Commonwealth of Kentucky.



President of Senate



Speaker-House of Representatives

Attest: 

Chief Clerk of Senate

Approved 

Governor

Date 
